

1 AN ACT in relation to aging.

2 Be it enacted by the People of the State of Illinois,  
3 represented in the General Assembly:

4 Section 1. Short title. This Act may be cited as the  
5 Family Caregiver Act.

6 Section 5. Legislative findings. The General Assembly  
7 recognizes the following:

8 (1) Family caregivers, serving without  
9 compensation, have been the mainstay of the long-term  
10 care system in this country. Care provided by these  
11 informal caregivers is the most crucial factor in  
12 avoiding or postponing institutionalization of the  
13 State's residents.

14 (2) Among non-institutionalized persons needing  
15 assistance with personal care needs, two-thirds depend  
16 solely on family and friends for assistance. Another 25%  
17 supplement family care with services from paid providers.  
18 Only a little more than 5% rely exclusively on paid  
19 services.

20 (3) Family caregivers are frequently under  
21 substantial physical, psychological, and financial  
22 stress. Unrelieved by support services available to the  
23 caregiver, this stress may lead to premature or  
24 unnecessary institutionalization of the care recipient or  
25 deterioration in the health condition and family  
26 circumstances of the caregiver.

27 (4) Two out of 3 family caregivers, due to being  
28 employed outside the home, experience additional stress.  
29 Two-thirds of working caregivers report conflicts between  
30 work and caregiving, requiring them to rearrange their  
31 work schedules, work fewer than normal hours, or take an

1 unpaid leave of absence. For this population, caregiver  
2 support services have the added benefit of allowing  
3 family caregivers to remain active members of our State's  
4 workforce.

5 Section 10. Legislative intent. It is the intent of the  
6 General Assembly to establish a multi-faceted family  
7 caregiver support program to assist unpaid family caregivers,  
8 who are informal providers of in-home and community care to  
9 frail individuals or children.

10 Services provided under this program shall do the  
11 following:

12 (1) Provide information, relief, and support to  
13 family and other unpaid caregivers of frail individuals.

14 (2) Encourage family members to provide care for  
15 their family members who are frail individuals.

16 (3) Provide temporary substitute support services  
17 or living arrangements to allow a period of relief or  
18 rest for caregivers.

19 (4) Be provided in the least restrictive setting  
20 available consistent with the individually assessed needs  
21 of the frail individual.

22 (5) Include services appropriate to the needs of  
23 family members caring for the frail individual, including  
24 a frail individual with dementia.

25 (6) Provide family caregivers with services that  
26 enable them to make informed decisions about current and  
27 future care plans, solve day-to-day caregiving problems,  
28 learn essential care giving skills, and locate services  
29 that may strengthen their capacity to provide care.

30 Section 15. Definitions. In this Act:

31 "Child" or "children" means an individual or individuals  
32 18 years of age or under.

1 "Department" means the Department on Aging.

2 "Eligible participant" means a family caregiver or a  
3 grandparent or older individual who is a relative caregiver.

4 "Family caregiver" means an adult family member, or  
5 another individual, who is an informal provider of in-home  
6 and community care to a frail individual.

7 "Family caregiver support services" includes, but is not  
8 limited to, the following:

9 (1) Information to caregivers about available  
10 services.

11 (2) Assistance to caregivers in gaining access to  
12 the services.

13 (3) Individual counseling, organization of support  
14 groups, and caregiver training for caregivers to assist  
15 the caregivers in making decisions and solving problems  
16 relating to their caregiving roles.

17 (4) Respite care provided to a frail individual  
18 that will enable caregivers to be temporarily relieved  
19 from their caregiving responsibilities.

20 (5) Supplemental services, on a limited basis, to  
21 complement the care provided by the caregivers.

22 (6) Other services as identified by the Department  
23 and defined by rule.

24 "Frail individual" means an older individual who is  
25 determined to be functionally impaired because the individual  
26 (i) is unable to perform from at least 2 activities of daily  
27 living without substantial human assistance, including verbal  
28 reminding, physical cueing, or supervision or (ii) due to a  
29 cognitive or other mental impairment, requires substantial  
30 supervision because the individual behaves in a manner that  
31 poses a serious health or safety hazard to the individual or  
32 to another individual.

33 "Grandparent or older individual who is a relative  
34 caregiver" means a grandparent or step-grandparent of a

1 child, or a relative of a child by blood or marriage, who is  
2 60 years of age or older and who:

3 (1) lives with the child;

4 (2) is the caregiver for the child because the  
5 child's biological or adoptive parents are unable or  
6 unwilling to serve as the primary caregiver for the  
7 child; and

8 (3) has a legal relationship to the child, such as  
9 legal custody or guardianship, or is raising the child  
10 informally.

11 "Informal provider" means an individual who is not  
12 compensated for the care he or she provides.

13 "Older individual" means an individual who is 60 years of  
14 age or older.

15 "Respite care" means substitute supports or living  
16 arrangements provided on an intermittent, occasional basis.  
17 The term includes, but is not limited to, in-home respite  
18 care, adult day care, child care, and institutional care. The  
19 term also includes respite care as defined in Section 2 of  
20 the Respite Program Act to the extent that such services are  
21 allowable and participants are eligible under the National  
22 Family Caregiver Support Program.

23 Section 16. Family caregiver demonstration grant. The  
24 Department shall seek federal funding for the establishment  
25 and assessment of a Family Caregiver Training and Support  
26 Demonstration Project using residential facilities licensed  
27 under the Nursing Home Care Act. The Department is  
28 authorized to fund 2 sites, one in a rural community and one  
29 in a more urban area. The Department shall adopt rules  
30 governing participation and oversight of the program. The  
31 Department shall seek technical assistance from the  
32 Department of Public Aid. The Department shall advise the  
33 Governor and the General Assembly regarding the effectiveness

1 of the program within 6 months after the conclusion of the  
2 demonstration period.

3 Section 20. Powers and duties of the Department. The  
4 Department shall administer this Act and shall adopt rules  
5 and standards the Department deems necessary for that  
6 purpose. At a minimum, those rules and standards shall  
7 address the following:

8 (1) Standards and mechanisms designed to ensure the  
9 quality of services provided with assistance made  
10 available under this Act.

11 (2) Data collection and record maintenance.

12 The Department shall administer this Act in coordination  
13 with Section 4.02 and related provisions of the Illinois Act  
14 on the Aging.

15 Section 25. Provision of services. The Department shall  
16 contract with area agencies on aging and other appropriate  
17 agencies to conduct family caregiver support services to the  
18 extent of available State and federal funding. Services  
19 provided under this Act must be provided according to the  
20 requirements of federal law and rules.

21 Section 35. Health care practitioners and facilities not  
22 impaired. Nothing in this Act shall impair the practice of  
23 any licensed health care practitioner or licensed health care  
24 facility.

25 Section 40. Entitlement not created; funding; waivers.

26 (a) Nothing in this Act creates or provides any  
27 individual with an entitlement to services or benefits. It is  
28 the General Assembly's intent that services under this Act  
29 shall be made available only to the extent of the  
30 availability and level of appropriations made by the General

1 Assembly.

2 (b) The Director may seek and obtain State and federal  
3 funds that may be available to finance services under this  
4 Act, and may also seek and obtain other non-State resources  
5 for which the State may be eligible.

6 (c) The Department may seek appropriate waivers of  
7 federal requirements from the U.S. Department of Health and  
8 Human Services.

9 Section 90. The Respite Program Act is amended by  
10 changing Sections 1.5, 2, 3, 4, 5, 6, 8, 11, and 12 as  
11 follows:

12 (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

13 Sec. 1.5. Purpose. It is hereby found and determined by  
14 the General Assembly that respite care provides relief and  
15 support to the primary care-giver of a frail ~~or--abused~~ or  
16 ~~functionally disabled or cognitively-impaired-elder~~ adult and  
17 provides ~~by--providing~~ a break for the caregiver from the  
18 continuous responsibilities of care-giving. Without this  
19 support, the primary care-giver's ability to continue in his  
20 or her role would be jeopardized; thereby increasing the risk  
21 of institutionalization of the frail ~~or--abused~~ or  
22 ~~functionally disabled or cognitively-impaired-elder~~ adult.

23 By providing ~~improving-and-expanding-the-in-home~~ respite  
24 care ~~services--currently--available~~ through intermittent  
25 planned or emergency relief to the care-giver during the  
26 regular week-day, evening, and weekend hours, both the  
27 special physical and psychological needs of the primary  
28 care-giver and the frail ~~or-abused~~ or ~~functionally disabled,~~  
29 ~~or cognitively-impaired-elder~~ adult, who is the recipient of  
30 continuous care, shall be met reducing or preventing the need  
31 for institutionalization.

32 Furthermore, the primary care-giver providing continuous

1 care is frequently under substantial financial stress.  
 2 Respite care and other supportive services sustain and  
 3 preserve the primary care-giver and family caregiving unit.  
 4 It is the intent of the General Assembly that this amendatory  
 5 Act of 1992 ensure that Illinois primary care-givers of frail  
 6 or abused or functionally disabled or cognitively-impaired  
 7 elder adults have access to affordable, appropriate in-home  
 8 respite care services.  
 9 (Source: P.A. 87-974.)

10 (320 ILCS 10/2) (from Ch. 23, par. 6202)

11 Sec. 2. Definitions. As used in this Act:

12 (1) "Respite care" means the provision of intermittent  
 13 and temporary substitute care or supervision of frail or  
 14 abused or functionally disabled or cognitively-impaired-elder  
 15 adults on behalf of and in the absence of the primary  
 16 care-giver, for the purpose of providing relief from the  
 17 stress or responsibilities concomitant with providing  
 18 constant care, so as to enable the care-giver to continue the  
 19 provision of care in the home. Respite care should be  
 20 available to sustain the primary care-giver throughout the  
 21 period of care-giving, which can vary from several months to  
 22 a number of years. Respite care can be provided in the home,  
 23 in a community-based day care setting during the day,  
 24 overnight, in a substitute residential setting such as a  
 25 long-term care facility required to be licensed under the  
 26 Nursing Home Care Act or the Assisted Living and Shared  
 27 Housing Act, or for more extended periods of time on a  
 28 temporary basis.

29 (1.5) "In-home respite care" means care provided by an  
 30 appropriately trained paid worker providing short-term  
 31 intermittent care, supervision, or companionship to the frail  
 32 or disabled adult in the home while relieving the care-giver,  
 33 by permitting a short-term break from the care-giver's

1 care-giving role. This support may contribute to the delay,  
 2 reduction, and prevention of institutionalization by enabling  
 3 the care-giver to continue in his or her care-giving role.  
 4 In-home respite care should be flexible and available in a  
 5 manner that is responsive to the needs of the care-giver.  
 6 This may consist of evening respite care services that are  
 7 available from 6:00 p.m. to 8:00 a.m. Monday through Friday  
 8 and weekend respite care services from 6:00 p.m. Friday to  
 9 8:00 a.m. Monday.

10 (2) "Care-giver" shall mean the family member or other  
 11 natural person who normally provides the daily care or  
 12 supervision of a frail,--abused or disabled elderly adult.  
 13 Such care-giver may, but need not, reside in the same  
 14 household as the frail or disabled adult.

15 (3) (Blank). "Provider"--shall--mean--any--entity--enumerated  
 16 in--paragraph--(1)--of--this--Section--which--is--the--supplier--of  
 17 services--providing--respite.

18 (4) (Blank). "Sponsor"--shall--mean--the--provider,--public  
 19 agency--or--community--group--approved--by--the--Director--which  
 20 establishes--a--contractual--relationship--with--the--Department  
 21 for--the--purposes--of--providing--services--to--persons--under--this  
 22 Act,--and--which--is--responsible--for--the--recruitment--of  
 23 providers,--the--coordination--and--arrangement--of--provider  
 24 services--in--a--manner--which--meets--client--needs,--the--general  
 25 supervision--of--the--local--program,--and--the--submission--of--such  
 26 information--or--reports--as--may--be--required--by--the--Director.

27 (5) (Blank). "Director"--shall--mean--the--Director--of  
 28 Aging.

29 (6) "Department" shall mean the Department on Aging.

30 (7) (Blank). "Abused"--shall--have--the--same--meaning  
 31 ascribed--to--it--in--Section--103--of--the--Illinois--Domestic  
 32 Violence--Act--of--1986.

33 (8) "Frail or disabled adult" shall mean any person  
 34 suffering--from--Alzheimer's--disease who is 60 55 years of age

1 or older and ~~or--any--adult--60-years-of-age-or-older,~~ who  
 2 either (i) suffers from Alzheimer's disease or a related  
 3 disorder or (ii) is unable to attend to his or her daily  
 4 needs without the assistance or regular supervision of a  
 5 care-giver due to mental or physical impairment and who is  
 6 otherwise eligible for services on the basis of his or her  
 7 level of impairment.

8 (9) "Emergency respite care" means the immediate  
 9 placement of a trained, in-home respite care worker in the  
 10 home during an emergency or unplanned event, or during a  
 11 temporary placement outside the home, to substitute for the  
 12 ~~primary~~ care-giver. Emergency respite care may be provided  
 13 ~~in-the-home~~ on one or more occasions unless an extension is  
 14 deemed necessary by the case coordination unit. When there  
 15 is an urgent need for emergency respite care, procedures to  
 16 accommodate this need must be determined. An emergency is:

17 (a) An unplanned event that results in the  
 18 immediate and unavoidable absence of the ~~primary~~  
 19 care-giver from the home in an excess of 4 hours at a  
 20 time when no other qualified care-giver is available.

21 (b) An unplanned situation that prevents the  
 22 ~~primary~~ care-giver from providing the care required by a  
 23 frail or ~~abused-or-functionally~~ disabled ~~or--cognitively~~  
 24 ~~impaired~~ adult living at home.

25 (c) An unplanned event that threatens the health  
 26 and safety of the frail or disabled adult.

27 (d) An unplanned event that threatens the health  
 28 and safety of the ~~primary~~ care-giver thereby placing the  
 29 frail or ~~abused-or-functionally~~ disabled ~~or--cognitively~~  
 30 ~~impaired-elder~~ adult in danger.

31 (10) (Blank). "~~Primary--care-giver~~"--means--the-spouse,  
 32 relative,~~-or-friend,~~ 18-years-of-age-or-older,~~--who--provides~~  
 33 the--daily--in-home-care-and-supervision-of-a-frail-or-abused  
 34 ~~or-functionally-disabled-or-cognitively-impaired-elder-adult.~~

1 A-primary-care-giver-may, but-does-not-need-to, reside-in-the  
 2 same-household-as-the-frail-or-abused-or-functionally  
 3 disabled-or-cognitively-impaired-adult.-A-primary-care-giver  
 4 requires-intermittent-relief-from-his-or-her-caregiving  
 5 duties-to-continue-to-function-as-the-primary-care-giver.  
 6 (Source: P.A. 91-357, eff. 7-29-99; 92-16, eff. 6-28-01.)

7 (320 ILCS 10/3) (from Ch. 23, par. 6203)  
 8 Sec. 3. Respite Program. The Director is hereby  
 9 authorized to administer a program of establish-respite  
 10 projects-for-the-purposes-of-providing-care-and assistance to  
 11 persons in need and to deter the institutionalization of  
 12 frail or disabled or-functionally-disabled-or-cognitively  
 13 impaired adults.  
 14 (Source: P.A. 87-974.)

15 (320 ILCS 10/4) (from Ch. 23, par. 6204)  
 16 Sec. 4. No Limit to Care. Nothing contained in this Act  
 17 shall be construed so as to limit, modify or otherwise affect  
 18 the provisions, for long-term in-home services being provided  
 19 under-of Section 4.02 of the Illinois Act on the Aging.  
 20 (Source: P.A. 87-974.)

21 (320 ILCS 10/5) (from Ch. 23, par. 6205)  
 22 Sec. 5. Eligibility. The Department may establish  
 23 eligibility standards for respite services taking into  
 24 consideration the unique economic and social needs of the  
 25 population for whom they are to be provided. The population  
 26 identified for the purposes of this Act includes persons  
 27 suffering from Alzheimer's disease or a related disorder and  
 28 persons who are 60 55 years of age or older, or--persons--age  
 29 60-and-older with an identified service need. Priority shall  
 30 be given in all cases to frail,--abused or functionally  
 31 disabled or-cognitively-impaired adults.

1 (Source: P.A. 87-974.)

2 (320 ILCS 10/6) (from Ch. 23, par. 6206)

3 Sec. 6. Responsibilities. The--following--requirements  
4 shall--apply--for--any-projects-authorized-under-Section-3-of  
5 this-Act:

6 (a) The Department Director shall administer this Act  
7 and shall adopt rules and standards the Department deems  
8 necessary for that purpose establish--target--areas--needing  
9 respite-care-services.

10 (b) The Department Director shall make grants to or  
11 contract with Area Agencies on Aging and other appropriate  
12 community-based organizations to provide respite care under  
13 this Act publicize-the--existence--of,--and--make--available,  
14 application-forms-for-sponsors-seeking-to-establish-a-respite  
15 program.

16 (c) (Blank). The--application--forms--shall-require-the  
17 following-information-and-any-other-information-the--Director  
18 deems-necessary:

19 (1)--Identity-and-qualifications-of-a-sponsor.

20 (2)--Identity-and-qualifications-of-a-provider-and-a  
21 plan-for-the-coordination-of-services.

22 (3)--An--assessment--of--the-community-need, support  
23 and-participation-for-respite-services.---The--assessment  
24 shall-include-documentation.

25 (4)--Plans--for--the-coordination-and-arrangement-of  
26 provider-services-in-a-manner-that-meets-client-needs.

27 (5)--A-fiscal-plan,--including--specific--provisions  
28 for-the-utilization-of-existing-reimbursement-and-funding  
29 sources-and-the-development-of-local-financial-support.

30 (6)--Plans---for--publicizing--the--purpose--of--the  
31 project-and-the-services-to-be-provided.

32 (7)--Certification-of-licensure-or-certification--of  
33 any--individual,--agency--or--family--providing-a-service

subject-to-licensure, or certification under State law.

(d) (Blank). The Director shall review and evaluate each application and present each application for review and evaluation by the Council on Aging established under Section 7 of the Illinois Act on the Aging. The Council and the Department shall approve a number of applications and, within the amounts appropriated, award grants for the operation of respite programs.

(e) (Blank). The application approved by the Director and the Council on Aging shall be the service plan of the provider. The Director shall ensure that each service plan is coordinated with the designated area agency provided for in Sections 3.07 and 3.08 of the Illinois Act on the Aging, the local public health authority, and any other public or private service provider to ensure that every effort will be made to utilize existing funding sources and service providers and to avoid unnecessary duplication of services.

(f) Nothing in this Act shall be construed to limit, modify, or otherwise affect the provision of long-term in-home services under Section 4.02 of the Illinois Act on the Aging.

(Source: P.A. 87-974.)

(320 ILCS 10/8) (from Ch. 23, par. 6208)

Sec. 8. Funding. Services Respite projects authorized under this Act shall be funded only to the extent of available appropriations for such purposes. The Director may shall seek and obtain State and federal funds that may be available to finance respite care grants awarded under Section 6 of this Act, and may shall also seek and obtain other non-state resources for which the State may be eligible. Implementation of projects under this Act shall be contingent upon the availability of federal financial participation. To the extent necessary for implementation of

1 ~~this-Act~~, The Department may shall seek appropriate waivers  
2 of federal requirements from the U.S. Department of Health  
3 and Human Services.

4 (Source: P.A. 87-974.)

5 (320 ILCS 10/11) (from Ch. 23, par. 6211)

6 Sec. 11. Respite Care Worker Training.

7 (a) A respite care worker shall be an appropriately  
8 trained individual whose duty it is to provide in-home  
9 supervision and assistance to a frail ~~or---~~abused or  
10 functionally disabled ~~or-cognitively-impaired-elder~~ adult in  
11 order to allow the ~~primary~~ care-giver a break from his or her  
12 continuous care-giving responsibilities.

13 (b) The Director may prescribe minimum training  
14 guidelines standards for respite care workers to ensure that  
15 the special needs of persons receiving services under this  
16 Act and their ~~primary~~ caregivers will be met. The Director  
17 may designate Alzheimer's disease associations and community  
18 agencies to conduct such training. Nothing in this Act  
19 should be construed to exempt any individual providing a  
20 service subject to licensure or certification under State law  
21 from these requirements.

22 (Source: P.A. 87-974.)

23 (320 ILCS 10/12) (from Ch. 23, par. 6212)

24 Sec. 12. Annual Report. The Director shall submit a  
25 report each year to the Governor and the General Assembly  
26 detailing the progress of the respite care services provided  
27 ~~programs-established~~ under this Act. ~~The--report--shall~~  
28 ~~include:~~

29 (a) ~~--a-financial-report-for-each-program;~~

30 (b) ~~--a-qualitative-and-quantitative-profile-of-sponsors,~~  
31 ~~providers, care-givers-and-recipients--participating--in--the~~  
32 ~~program;~~

1           (c)---a---comparative---assessment---of---the---costs---and  
2           effectiveness-of-each--10rvice--or--combination--of--services  
3           provided;

4           (d)---an-assessment-of-the-nature-and-extent-of-the-demand  
5           for-services;-and

6           (e)---an--evaluation--of--the--success--of--programs--receiving  
7           grants-for-services-

8           (Source: P.A. 87-974.)

9           (320 ILCS 10/7 rep.)

10          (320 ILCS 10/9 rep.)

11          (320 ILCS 10/10 rep.)

12          Section 91. The Respite Program Act is amended by  
13          repealing Sections 7, 9, and 10.

14          Section 99. Effective date. This Act takes effect upon  
15          becoming law.